Perceived Colorectal Cancer Candidacy and the Role of Candidacy in Colorectal Cancer Screening

Annemieke P. Bikker[a], Sara Macdonald*[b], Kathryn A. Robb[b] , Ellie Conway[b], Susan Browne[b], Christine Campbell[a], David Weller[a], Robert Steele[c], Una Macleod[d]

[a] Usher Institute, The University of Edinburgh, UK; [b]Institute of health and Wellbeing, University of Glasgow, UK; [c]Medical Research Institute, University of Dundee; [d]Hull York Medical School, University of Hull, UK

[*]Corresponding author. Email: sara.macdonald@glasgow.ac.uk

Abstract

Screening is a well-established tool to advance earlier cancer diagnosis. We used Davison's concept of 'candidacy' to explore how individuals draw on collectively constructed images of 'typical' colorectal cancer (CRC) sufferers, or 'candidates', in order to evaluate their own risk and to ascertain the impact of candidacy on screening participation in CRC. We interviewed 61 individuals who were invited to participate in the Scottish Bowel Screening Programme. Of these, 37 were screeners (17 men and 20 women) and 24 non-screeners (13 men and 11 women). To analyse these data we used a coding frame that drew on: symptoms, risk factors, and retrospective and prospective candidacy. Few participants could identify a definite bowel cancer candidate and notions of candidacy were largely predicated on luck in the sense that anyone could be a candidate for CRC and there was little evidence to support a linear relationship between feelings of risk and screening decisions. Often participants described screening as part of a wider portfolio of being healthy and referred to feeling obliged to look after themselves. Our study suggests that rather than candidates for bowel cancer, screeners viewed themselves as candidates for screening by which screening decisions pointed towards the acceptance and normalisation of the rhetoric of personal responsibility for health. These findings have related theoretical and practical implications; the moral structure that underpins the new public health can be witnessed practically in the narratives by which those who see themselves as candidates for screening embrace wider positive health practices.

Keywords

Candidacy, risk, lay epidemiology, colorectal cancer, screening, qualitative interviews

Introduction

In this paper we turn attention to the wider social context in which screening decisions are made. In particular we explore the understanding of how bowel cancer risk perceptions are arrived at and the utility of lay epidemiology and cancer candidacy in explaining bowel cancer screening decisions (Davison, Frankel & Davey-Smith 1991; Macdonald, Watt & Macleod 2013). Given that eligibility is wide, indeed wider than the incidence of bowel cancer, we sought to ask how those eligible for bowel screening arrive at participation decisions and further how they decide that they are a) candidates for bowel cancer and b) candidates for bowel cancer screening and ask whether perceived candidacy impacts on participation in the Scottish Bowel Cancer Screening programme. We address these questions by examining the data collected through 61 interviews with individuals who either decided or decided not to participate in the Screening programme.

Cancer screening and risk

Screening is a well-established tool used in measures that seek to advance earlier cancer diagnosis. Successful screening programmes offer tangible benefits: decreases in overall cancer deaths, earlier diagnoses and associated reductions in harmful treatments, and improvements in survival and survivorship (Neal et al., 2015; Richards, 2009). Yet, screening is not without harm or controversy. From a biomedical perspective, false-positives subject participants to unnecessary tests and treatment while false negatives provide unwarranted reassurance. Moreover, questions persist surrounding the over-diagnoses of early cancers that may never progress to life-threatening disease (Grimes & Schulz, 2002; Rose, 1985).

Outside of medicine, wider concerns have emerged. The steady creep of the risk society (Beck, 1992; Giddens, 1990) into all aspects of life and the attendant rise of surveillance

medicine (Armstrong, 1993, 1995) has altered and narrowed the space between health and illness. The ability not only to identify illness before it happens but also to highlight 'risk factors' that make illness more likely heaps scrutiny on individuals and populations alike. Risk therefore widens, making it impossible to avoid. Yet, the ever-increasing focus on individual responsibility and the rhetoric of the 'new' public health (Green, Mitchell & Bunton, 2010) implies that risk can be bypassed by making appropriate choices. Health practices therefore inhabit 'a new morality' and enacting personal responsibility has become synonymous with virtue (Bunton, Nettleton & Burrows, 1995). Failure to engage and make 'good' decisions is seen as irrational; skirting social duty (Howson, 1998). Screening programmes have been identified as critical sites for studying surveillance *en masse*. Howson's work on cervical screening draws out the inherently moral and obligatory nature of national screening programmes which assume rational and objective responses to invitations to screen; however, they fail to acknowledge that invitations are received in a socially contingent context characterised by interactional experience (Howson, 1999). Howson notes that explorations of responses to screening typically seek to address gaps in knowledge and ultimately seek to increase participation. In such a morally loaded discourse it is challenging to consider the associated ability of patients to execute a genuinely 'informed choice' (Fox, 2006). Although the information accompanying cancer screening invitations now highlight harms alongside benefits, deliberate policy decisions on what information to include and how to present it, can obscure informed choice. For example, the cervical screening programme in New Zealand attempted to remove stigma associated with sexual risk factors by omitting information on risks associated with sexual behaviour (Braun & Gavey, 1999). The intrinsic friction in programmes that must simultaneously advocate individual level choice but promote population level public health benefit (Jepson, 2009) has led some to question the ability to arrive at truly 'informed choice' (Armstrong & Murphy, 2008). Moreover, if the

success of cancer screening programmes depends on uptake, the emphasis, and the information provided to those invited to screen must lean, albeit implicitly, towards participation.

Decisions or responses to invitations to cancer screening programmes are therefore crucial. Previous studies of decisions around participation reveal links with a range of socio-demographic factors, principally socio-economic status and ethnicity as well as a range of individually held social cognitive factors that draw on the essential components that underpin widely used psychological models, such as the Health Belief Model (Becker, 1974) and the Theory of Planned Behaviour (Ajzen, 1985). Perceived severity, perceived susceptibility, perceived benefits and barriers as well as self-efficacy coalesce to inform decisions. Collectively studies of participation in bowel cancer screening report typically negative perceptions of screening, and of cancer as well as a general lack of knowledge about bowel cancer amongst those who opt not to screen; while those who do screen believe that participation will reduce their risk of dying (Honein-AbouHaider, et al., 2016; Hvidberg, Flytkjær Virgilsen, FischerPedersen & Vedsted, 2019). However, the presence of positive social cognitive beliefs has been shown to mediate socio-economic differences in uptake of bowel cancer screening (Lo et al., 2015).

While perceived susceptibility or perceived risk is only one among many influences on decisions, previous studies hint that perceptions of risk are important. Indeed, by inviting only a sub-section of the population to participate in cancer screening, programmes imply heightened risk for those invited. Although eligibility is wide, findings suggest that participation is strongly socially patterned and varies both across programmes (for example higher uptake for breast cancer when compared to bowel cancer), and across communities

(affluent versus deprived) (ISD Scotland 2018a). Studies of cancer risk perceptions are common. These range from large studies that judge awareness of cancer risk factors (Redeker, Wardle, Wilder Hiom & Miles, 2004) to smaller qualitative studies that provide a more in-depth analysies of individual risk perception and risk attribution (Robb et al., 2007), and, taken together these studies demonstrate the variability and complexity of risk awareness and perception. Studies conclude that relationships between awareness of risk and behaviour change are typically complex (Dillard, Ferrer, Ubel & Fagerlin, 2012; Weinstein et al., 2007), and although links have been made between perceived risk and behaviour, few people see themselves as 'at risk' (Hay, Coups & Ford, 2006). Certainly, experience of cancer amongst family and friends has been shown to impact on understanding of risk (Redeker et al., 2004) but this is limited to individual level experience. The variation in uptake implies that perceived susceptibility, risk and informed decisions may be made in quite different, socially contingent ways. While we know about reasons for uptake and barriers to participation at an individual level, we know less about wider social influences on screening decisions.

Before going on to detail our findings it is useful to look in more depth at both bowel cancer screening in Scotland and at lay epidemiology.

Screening for bowel cancer

Bowel cancer is increasingly common and is currently the fourth most common cause of cancer death worldwide (Ferlay et al., 2012). In 2009 the bowel cancer screening programme became the third national UK screening programme, joining breast and cervical screening both established in 1988. All programmes are managed by the National Health Service (NHS) screening programme and those identified as at risk are invited to participate at fixed time points. Unlike breast and cervical screening however, bowel cancer screening is carried out

independently by the recipient in their own home. Indeed, placing the responsibility on the recipient to undertake the bowel screening test and, in particular the 'yuck factor' associated with handling faeces have also both been offered as explanations for lower uptake of bowel cancer screening (Palmer et al., 2014). Since the bowel screening programme was introduced more than 1.5 million people aged 50-74 receive the Faecal Occult Blood Test (FOBT) by post every two years. Individuals are asked to collect stool samples and return the kit to the Scottish Bowel Cancer Screening Programme, who test the sample for blood in the stool. More recently the programme has replaced FOBT with the Faecal Immunochemical Test (FIT), which requires only one stool sample and is thought to simplify the process for recipients (Scottish Government, 2017).

Since its inception uptake of the Scottish bowel cancer screening programme has plateaued at 57%, slightly lower than the population target of 64%. However, the average masks large variation across different socio-demographic groups. Uptake is consistently higher amongst women and participation decreases with increasing deprivation. For example, in 2017 uptake by males living in the most deprived areas was 40.7% and for women 45.2%. The uptake by males living in the least deprived areas was 61.8% and for women this figure was 68.9% (ISD Scotland, 2018b). Age, sex, and deprivation are commonly associated with bowel cancer screening uptake in the quantitative literature (Mansouri, McMillan, Grant, Crighton & Horgan, 2013; Quyn et al., 2018), though the underlying causes of these variations are less explored. Qualitative studies suggest that higher levels of poor health literacy among people in more deprived areas contributes to the lower uptake (Honein-AbouHaider et al., 2016).

Lay epidemiology, risk and candidacy

As already noted, population level cancer screening programmes target those individuals deemed to be 'at risk', and in the UK programmes, eligibility is defined according to age and, for breast and cervical cancer, sex. So, how do the eligible arrive at their understanding of risk or ideas about screening? It is most likely that those eligible will have a preconceived notion of cancer and cancer risk based on past experience; in essence they are already 'lay epidemiologists' (Davison et al., 1991). Davison and colleagues' work on coronary heart disease in Wales during the late 1980's concluded that within communities individuals drew on a range of informational sources and observed events at micro, meso and macro levels when thinking about illness and risk. Lay epidemiology offers a socially influenced mechanism to think about risk and subsequent behaviour and has been applied to areas such as decisions around drug use (Miller, 2005), vaccinating children (Pihl, Johannessen, Ammentorp, Jensen & Kofoed, 2017) and drinking guidelines (Lovatt, Eadie, Meier et al., 2015). Together these studies show that communities of belief are formed and influence responses to risk. Central to Davison's conceptualisation of lay epidemiology are popular understandings of 'coronary candidacy', which reflects a culturally embedded and widely shared understanding of illness and provided Davison's participants with a shorthand aid to the estimate of risk (Davison et al., 1991). Coronary candidates were identified as middle-aged, overweight men, known for unhealthy behaviours, such as smoking or the consumption of fatty food and/or beer. Physical appearance was an affirmation of risk and often lay characterisations of coronary candidacy were strongly aligned with mainstream bio-medical 'risk' profiles. Candidacy was created and reproduced in cultural contexts. Importantly candidacy is fallible: anomalies exist and prompt re-evaluation of perception. Candidacy therefore challenges us to ask more nuanced questions about risk that pools cultural understanding and focuses on who is at risk? Why that individual in particular? What do they look like? And crucially, what do they have in common and am I like them?

Applying Davison's original concept of candidacy has been considered in the realm of cancer and cancer screening (Macdonald et al., 2013; Pfeffer, 2004). Macdonald and colleagues found that the information gathering processes as described by Davison were reflected when discussing cancer and cancer risk, but concluded that with the exception of smoking, cancer candidacy was less explicit. Instead much of the discussion of cancer drew on common and shared narratives of cancer as a severe, unpredictable and ungovernable illness (Macdonald et al., 2013). Candidacy was found to be important when conceptualising personal risk amongst black and minority ethnic women eligible for breast screening but the impact of candidacy on screening participation was unclear (Pfeffer, 2004). In this paper we build on this knowledge by exploring collective notions of colorectal cancer candidates (the type of person who develops bowel cancer) and considering the role of candidacy in decisions about participation in the Scottish bowel cancer screening program.

Methods

This study was the second phase of a broader qualitative research project that explored ideas about candidacy or risk of illness and considered if this is important when cancer patients appraise their symptoms (part 1) or individuals decide whether to take part in bowel cancer screening (part 2). The first part was conducted through a secondary qualitative data analysis of interviews with colorectal patients, and the findings of this phase have been published elsewhere (see Macdonald et al., 2019). For the second (and current) study we selected interviews because of the potential of sensitive and private issues being raised by participants (Kvale & Brinkman, 2009). The interviews were semi-structured to ensure some consistency across interviews and allow us to compare and gain insight into participants' understandings and experiences of bowel cancer and bowel cancer screening.

Recruitment, Setting and Sample

We conducted semi-structured interviews with individuals eligible for the Scottish Bowel Screening programme, living in the NHS Greater Glasgow and Clyde region in the 2013/2014 invitation round. The NHS Glasgow and Clyde region is a mixed, predominantly urban area and holds 80% of the most deprived areas in Scotland. Those who according to the Information Services Division (ISD) of NHS Scotland had been invited and participated in the latest round of the bowel screening programme (in this paper called screeners)[1] and those who had been invited but not participated in the latest round of the bowel screening programme (in this paper called non-screeners) were purposively 'matched' for age, sex and socio-economic status. Socio-economic status was based on the Scottish Index of Multiple Deprivation (SIMD) which utilises postal code districts, with SIMD 1 referring to the most deprived areas and SIMD 5 to the least deprived areas. By matching individuals on the factors of age, sex, and deprivation, which are thought to influence bowel cancer screening uptake (Mansouri et al., 2013; Quyn et al., 2018) we aimed to reduce the effect of these so-called confounders in the data. The study aimed to include at least 20 pairs.

Following identification of potential participants by the ISD of NHS Scotland, study invitations were sent by post from the Scottish Bowel Screening Programme who distributed the invitations on behalf of the research team.

In total 83 recruitment packs were posted to screeners of which 28 (33.7%) agreed to participate in the study, and 1058 packs were sent to non-screeners of which 20 (1.9%)

[1] In this paper we use the term "screener" to refer to a screening participant. This may be different from the medical literature in which the term "screener" is usually used to refer to a service provider, e.g. someone who works in the screening centre or performs colonoscopy or mammography etc.

agreed to participate. Based on previous literature (e.g. Hall et al., 2016; Mercer et al., 2018) we anticipated that the recruitment of non-screeners, and people in the more deprived areas would be challenging, and this was indeed the case. To reach our target of 20 matched pairs we sought ethical approval to augment recruitment via convenience sampling. Through snowball sampling and by contacting networks of community organisations, we recruited another nine screeners and four non-screeners. Due to ethical requirements the research team did not know any of the socio-demographical information about potential participants or whether they were screeners or a non-screeners until the participants contacted the team. All participants who agreed to an interview were interviewed. In this paper the analysis is based on the responses of all interview participants.

A total of 62 individuals agreed to be interviewed, but one interview was excluded because the participant was ineligible for the bowel screening programme. Of the remaining 61 interviewees 37 had taken part in the previous round of bowel cancer screening and 24 had not taken part in bowel cancer screening. In total 30 males and 31 females participated in the interview study and the mean age of participants was 64 years. More than half (33 participants) of those interviewed were from more deprived areas. Eight people had a previous/existing diagnosis of cancer, and two of those (both screeners) had previously had bowel cancer. All participants knew someone with cancer, and for most this was immediate family members, for example a third of all participants had had a parent with cancer, an experience that was evenly spread amongst screeners and non-screeners. The experience of common bowel cancer symptoms, such as altered bowel habit and rectal bleeding was shared amongst both groups, though more apparent in non-screeners. Socio-demographics by screening status are shown in table 1.

[*Table 1 here*]

Interviews took place between April and December 2014. Ethical Approval was obtained from the Newcastle and North Tyne REC (ref:13/NE/0112).

Data collection and analysis

Our focus on perceptions of risk, candidacy and screening participation from the outset provided the structure to guide the semi-structured interviews. However, the interview was flexible enough to allow interview participants the scope to introduce and focus on issues of personal relevance. We categorised a priori questions around five themes: awareness and perception of cancer and cancer screening in general, symptoms of bowel cancer, candidacy and bowel cancer risk, personal risk and experiences of bowel screening. Most interviews took place in the participants' own home, six in the University of Glasgow and nine over the phone. The interviews lasted between 20 minutes and one hour.

Interviews were recorded with consent, transcribed and anonymised. The interview transcripts were read and re-read carefully by AB and a selection by SM. Data were analysed by using a pragmatic grounded theory approach (Byrant, 2009). Here grounded theory is adapted to emphasise the importance of abduction and the insights that can be obtained from the literature prior to the data analysis. The underlying assumption is that there are no fixed points from which reality can be observed, and that insights can come from the data as well as from engaging with the literature (Byrant, 2009). Such an approach was particularly suited to this analysis given our a priori interest in 'cancer candidacy'. Following the careful reading

of eight transcripts AB and SM began to discuss and develop the coding framework, which drew on our presumptive overarching themes and sub-themes relating to the literature on cancer. Here we included: perception of cancer, hierarchy of risk factors, candidacy and risk (including retrospective and prospective candidacy), and positioning of own risk. Additional themes and sub-themes (including candidates to screening) were created through discussion and interpretation of the participants' accounts. The analytical coding frame was systematically applied to the remaining transcripts. This process led to some refinement of the initial codes and the creation of additional ones. NVivo software was used to facilitate the data management and record coding decisions.

In seeking to explore perceptions of bowel cancer candidacy and the potential impact of perceived candidacy on screening participation we arrived at four over-arching themes: 1) Shared cancer and bowel cancer narratives, 2) Bowel cancer candidacy: who is perceived to be at risk for bowel cancer, 3) Perceptions of personal candidacy and bowel cancer risk, and 4) Candidacy and candidates for screening. By representing participants' common cancer narratives, we set the context for a more thorough consideration of perceived bowel cancer risk, perceived bowel cancer candidacy and importantly introduced the largely unexplored idea of candidates for screening.

Findings

Shared cancer and bowel cancer narratives

Common cancer narratives that focused on cancer as the most feared of diseases were characterised throughout the interviews. Cancer was described as a terrifying and unpredictable disease irrespective of the proximity to cancer within the participants' social networks or the relationship with the cancer sufferer. One participant whose father as well as

close friend had suffered from cancer said that: *I think people are aware of cancer all the time and it's, people are terrified of it actually* (non-screener, female, 69 years, id 62).

Similar views were expressed by people who did screen, for example:

It [cancer] just seems to be one of those totally kind of unpredictable things you know (screener, female, 69 years, id 19).

However, as previous studies have shown, participants in both screening groups discussed these very negative and more positive aspects of cancer interchangeably (Robb et al., 2014). Both the benefits of early detection and improvements in cancer outcomes were also frequently introduced. However, the tone in which cancer was discussed was slightly different across groups; screeners were typically more positive and focused more on the importance of early diagnosis, treatment options and the increasing normalisation of talking about cancer in everyday life. Non-screeners conversely shared more negative cancer stories and were more likely to describe cancer as 'terror', and emphasised the harrowing nature of cancer treatment. Improvements in treatment were less acknowledged among non-screeners. Our findings mirror those of a recent Danish study that found more positive attitudes towards cancer in those who opted to participate in screening (Hvidberg et al., 2019).

One participant, who decided not to screen referred to 'the work' required of bowel cancer patients and alluded to a future with stoma and/or colostomy. Another non-screener, whose decision not to screen was closely related to her experience of nursing several close family members and friends with cancer emphasised her negative view not only of cancer diagnosis but also of treatment:

The treatment is worse than the disease; in my experience the treatment is worse than the disease. And I can understand that some people want to cling to life and take everything that the NHS will throw at them but I'm not one of them. Even going with my friend, and see

young men and young women, that is horrendous. It's not for me to put myself through what those people are going through (non-screener, female, 54 years, id 28,)

It was apparent from discussions with many of the participants that cancer was viewed as a generic illness, rather than a host of site-specific illnesses and sub-illnesses. So instead of specifically talking about bowel cancer screening, cancer screening was discussed in more general terms. Adopting such a catch-all term for cancer was less likely amongst those who were more familiar with bowel cancer and indeed knowledge and experience of bowel cancer was more apparent in the screening group. Some non-screeners had little close experience of bowel cancer but without hesitation continued to describe bowel cancer as a terrible disease.

Participants also discussed the imbalance in media coverage of certain cancer and commented that bowel cancer simply did not occupy the media space that breast cancer did, and therefore it was easy not to 'notice' bowel cancer until confronted with it. Though unable to estimate how common bowel cancer was one participant, who opted not to screen, supposed that bowel cancer must be *'reasonably [common], otherwise they wouldn't do these preventative tests* (non-screener, female, 63 years, id 48).

Cancer therefore was primarily seen as a 'terrifying' illness, though many also reflected on improvements in the overall cancer picture over time. However, it is notable that those who participated in screening had a slightly more positive experience of cancer, which has been reported elsewhere (Hvidberg et al., 2019). We now turn attention to participants' ideas of bowel cancer candidacy, and bowel cancer candidates.

Bowel Cancer Candidacy: who is perceived to be at risk of bowel cancer

Candidacy is arrived at by observing cases within families, social networks and wider society, and often it is illness events in the least likely, fit and healthy individuals that remain

striking (Davison et al., 1991). In relation to coronary disease Davison and colleagues (1991, page 14) concluded that "such violations, however, are readily incorporated into the explanatory model as a whole by the simple recognition that candidacy only indicates increased risk while death from heart attack remains famed for its caprice". As Davison demonstrated, the occurrence of both anomalous deaths and unwarranted survivors (those who do all the wrong things yet live long) forces us to question mainstream rhetoric about avoiding risk. Views of risk are challenged and throughout participants' accounts there were numerous stories of fit and healthy individuals with inexplicable cancers. These are the memorable cancer events and can lead to cancer sufferers and those around them to wonder what they 'did wrong', as the following extract suggests, as one participant recounted a conversation with a friend:

She was quite angry that she had the cancer because she didn't smoke and she didn't drink, and she went, why me, why have I got it, why is this disease attacking me? And I had to say, well, it attacks wee babies and toddlers and children. I says, we don't know the answer to that, I says, nobody does, you know (screener, female, 64 years, id 31).

That cancer is viewed as an unpredictable illness is evident in the above extract and common throughout the interviews. Anomalous cases coloured views of cancer and an already wide notion of risk became wider as stories of 'young, fit and healthy' individuals were frequently shared in interviews. Unpredictability therefore promoted the almost universally held notion that anyone can be a candidate for cancer, and this wide notion of candidacy was repeated across interviews by screeners and non-screeners alike.

Bowel cancer, I don't really know, being honest. And as I say, I don't think it hurts any certain type of person. Just anybody can get it. I've no opinion on it. The only opinion I have got is that it can hit anybody (non-screener, male, 70 years, id 3).

Settling firmly on a specific risk profile or 'candidate' for colorectal cancer was problematic even if participants had close experience of bowel cancer in their social networks. Yet, when participants speculated about risk factors they 'supposed' these were predominantly 'unhealthy, smoking, and eating the wrong things'. Alcohol consumption, obesity and eating a poor diet were consistently raised as potential risks or characteristics of bowel cancer candidates. Supposed candidacy characteristics were in direct contrast to the 'young, fit and healthy' narratives shared previously in relation to known cancer events in personal social networks. Here the idea of bowel cancer candidacy differed considerably from coronary candidacy as described by Davison and colleagues (Davison et al., 1991) where characteristic coronary candidates and risks were closely aligned with established biomedical risk factors. In the following extract the participant, a screener, articulated the tension between appreciation of risk factors and experiential knowledge:

I would tend to associate bowel cancer with people who eat too much, eat fatty foods and don't really have a healthy lifestyle, don't exercise and don't look after themselves, that might be totally wrong but that's my perception of it you know, but as I said a minute ago it can happen to anybody (screener, male, 54 years, id 17).

Balancing opposing views perhaps explains why many participants were tentative in their portrayal of bowel cancer candidates. Some commented that the interview was the first time that they had thought and indeed verbalised their thoughts on bowel cancer and bowel cancer risk. Participants were therefore equivocal about the relative importance of risk factors for bowel cancer. This was contrasted with other cancers like lung cancer and the strong association with smoking or sun exposure with skin cancer.

Well my father died of cancer, I've had two brothers die of cancer, but it was all lung cancer but I'm a non-smoker. Them three were heavy smokers (screener, male, 68 years, id 25).

There was an acknowledgement that risks of cancer and bowel cancer could be reduced by adhering to healthy lifestyle messages but doing so did not provide guarantees. Despite introducing 'logical' risks and behaviours likely to be associated with bowel cancer, the emphasis across the interviews was the randomness of cancer. In this sense luck essentially 'trumped' other factors because anomalies – whether healthy yet get cancer or unhealthy and remain well – reinforced doubt. Opinions of candidacy and risk were therefore often adapted to accommodate new information as the following extract demonstrates:

Well I used to think years ago it was because of your lifestyle but it's not I found that out with that lady in hospital, she had a better diet than I had, she exercised more than I did and yet she took bowel cancer. It can happen to anybody no matter what your lifestyle is I think, I think some cases your lifestyle doesn't help (screener, female, 70 years, id 39).

Uncontrollable biological factors such as family history and age were mentioned though the identification of age as a risk factor was often precipitated by the invitation to screen around the time of participants' 50th birthday. Participants who knew someone close to them who (had) suffered from bowel cancer or had bowel cancer themselves mentioned possible non-modifiable risk factors, rather than lifestyle risk factors, which demonstrated a tendency to distance oneself or family members from blame or personal responsibility. For example, one participant talked about her mother who had been diagnosed with bowel cancer but did not consider behavioural factors:

The risk factors, when you get it down to it, trying to think about why my mother would have it [bowel cancer] we just hadn't a clue why it could occur...

It's hard to pinpoint. I know that there seems to be something going about that some cancers seem to be, kind of, genetic. But I don't know enough about that either…As I got older you

seem to accept it's just, kind of, part of life, seem to get cancer (screener, female, 75 years, id 21).

Reluctance to assign candidacy, as illustrated in the above quote, reflects Davison and colleagues' (1991) findings in relation to coronary candidacy, who noted that many of the behaviours that become part of a candidacy profile are often seen as lifestyle choices. Assigning candidacy therefore requires judging individual behaviour and there is reluctance to either identify with the characteristics and behaviours of candidates (Pfeffer 2004), or protect oneself or family members from accusations or criticism (Macdonald et al., 2013). In essence, the emphasis on the random nature of cancer makes this distance more rational and reasonable.

The typically negative views of cancer together with a hesitancy around attributing candidacy to others across both those who participated in screening and those who did not is significant. Participatory decisions - both to screen or to not - appeared to be located in very similar contexts. What then informed the decision? We focus now on exploring how participants regarded their personal risk or candidacy for bowel cancer.

Perceptions personal candidacy and bowel cancer risk

Just as participants were reluctant to assign candidacy to others, they were equally resistant to consider their own candidacy. Davison and colleagues (1991) noted that participants found it difficult to align the abstract nature of (cancer) risk with their own behaviour especially if it involved discussing the 'wrong' lifestyle choice. Participants in this study were equally keen to distance themselves from cancer risk and drew on the broader context and assumed that everyone was at risk. Participants were egalitarian in their risk and often reflected that they

felt no more at risk ‘than anyone else’; this egalitarianism offered the ‘safest’ position when discussing cancer, an illness that is feared and unpredictable.

Despite initial reticence, participants did go on to discuss their perceived personal risk in more detail, and often accounts were replete with contradictions – where participants contemplated their own risk while simultaneously creating space between themselves and perceptions of risk. Yet, there were clear contrasts in the way in which screeners and non-screeners discussed their own risk. Screeners tended to be more ambiguous about their own risk of bowel cancer throughout the interviews and often described themselves as both at risk and not at risk at different points in the interview. Screeners drew on several factors to illuminate views on their own candidacy, including what they observed in (healthy) others either directly or through the media, which in turn could create awareness of their own vulnerability. At times screeners framed their risk in relation to the perceived risk factors of age (partly due to the invitation to screen), genetic inheritance and diet. However, just as participants could be positive and negative about cancer, screeners both distanced and associated themselves with perceived risk factors. Some reflected on this contradiction as the following extract shows:

Well I think if you have a first degree relative who has cancer it makes me aware that my risk is probably slightly higher than of a person who doesn’t have that but the fact that she developed it at a very advanced age in her 90’s I think makes it probably a less strong risk factor (screener, male, 52 years, id 45).

In contrast, non-screeners expressed their risk unequivocally; either at risk or not at risk. Such certainty may in part be explained by a more symptom-driven approach to risk. Non-screeners tended not to feel at risk if they had not experienced bowel symptoms, as one participant stated *“I’m as regular as clockwork”* (non-screener, female, 54 years, id 28) or

"If no symptoms why worry" (non-screener, female, 77 years, id 37). The opposite was also true: if people experienced undiagnosed symptoms that were perceived to be potential indications of bowel cancer they felt at risk. For example, one non-screener who had experienced blood in his stool regarded himself as at risk but felt unable to participate in the screening programme, *"because I'm not going down the road of surgery"* (non-screener, male, 56 years, id 40). Also, a number of non-screeners with bowel symptoms had had previous investigations and were either being treated for another condition, for example diverticular disease or pulmonary embolism, or had received an 'all clear' after an endoscopy or colonoscopy and which they believed negated the need for further tests.

Non-screeners also positioned themselves more clearly closer to or further from perceived risk factors of bowel cancer. One participant who chose not to screen because she failed to see herself as a candidate for bowel cancer characterised bowel cancer as a gendered disease. She was clear that she was not at risk:

This sounds really silly, and I don't know why, but to me, the kind of person, who's going to get bowel cancer, is, a middle aged, overweight man (non-screener, female, 58 years, id 61).

While some non-screeners did not perceive themselves to be susceptible to the risk of bowel cancer, because they had no family history of the disease and/or had a healthy diet, the opposite was also true:

I would imagine it would be somebody like myself [who is at risk] a smoker, drinking, eating like diet … and things like that because you do hear a lot on the TV about obese people get all different heart problems and different illnesses (non-screener, female, 54 years, id 38).

The ambiguity expressed by those who participated in screening is compelling. It potentially indicates the importance of 'peace of mind' provided by screening, which essentially confirms 'good' health, assumed by those who participate in screening (Barnett at al., 2018).

Those who described choosing not to screen were much clearer in their attribution of personal candidacy; some were adamant that they were neither at risk or imagined that they had cancer, while a smaller number saw themselves as bowel cancer candidates and imagined the disease but 'would rather not know'. There was a sense among non-screeners that they were hesitant about seeking out or confirming risk, which is a resistant response to increased personal surveillance (Armstrong, 1995). The acceptance (or not) of increased surveillance and the introduction of risk was for some foregrounded in their response to screening invitations and we found this across participants accounts. Here we introduce and discuss the idea of 'candidates for screening'.

Candidacy, and candidates for screening

Screening was in principle universally supported. Irrespective of participation, screening was regarded as a valuable tool in the quest for early diagnosis and therefore an opportunity to access an 'early warning system'. It was also clear across interviews that perceived risk, or a lack thereof, were not straightforward motivators in decisions around screening participation. Rather screening decisions were based on a host of influences. For many of those who chose to screen, participation in the screening programme was an addition to their already healthy lifestyle portfolio. Screeners stressed the importance of early detection and offered examples of family members and friends who had benefited from early detection:

I think they did yeah that's my belief anyway and I don't know well I do have personal experience that's picked up a problem in one of my family member's bowels so it's, I would definitely advise everybody to have it done (screener, female, 69 years, id 8).

Observed cancer events especially in fit and healthy individuals encouraged risk avoidance behaviour and for some screening is an integral part of this. Across the interviews, there were

many examples of the influence of cancer cases on feelings of vulnerability to cancer and consequent screening behaviour. For some, such cases made them more determined to engage with screening programmes.

Yes, well, I suppose, from a… I'm, personally, happy to do it. I know, I understand why I should do it. Having lost, I think it was four people to cancer. I mean, my dad died this year, actually, which was secondary cancer of the liver, but it was more likely bowel cancer, colon or something round, in that area (screener, male, 56 years, id 44).

One participant who had not screened in the past became a screener after her sister was diagnosed with bowel cancer. Interestingly, the test mitigated her feelings of being at risk herself.

No, no, no, no I don't [feel at risk] *even although my sister had it but I don't, I don't know maybe that's silly to think like that but I really don't feel at risk. Don't get me wrong if I didn't do the test I think it would be oh that could be there or whatever but I think 'no' if you do the test it kind of reassures you (screener, female, 57 years, id 26).*

Here despite screening the participant is clear that she is not at risk and engaged in screening to confirm what she knew – that she did not have bowel cancer, and to reduce her risk. The belief that participating in the test itself reduces the feeling of risk was not uncommon. Throughout the interviews screeners discussed the reassurance, or peace of mind gained from participating, with the implication being an assumption that the test would be clear. In essence, screeners were participating to confirm that they did not have cancer.

I am a worrier by nature but it's yes I'd be worried and that's why I would do any test you know, just to get the reassurance that things are ok that you could sleep easy (screener. male, 54 years, id 17).

Screening also held a wider significance beyond the individual and a number of participants stated that they felt obliged to screen. Screening was seen as something that the National Health Service, and by extension the country had invested in, with good intention and as such failure to participate was wasting a valuable resource. Many participants discussed the 'prevention is better than cure' adage and this was not simply for individual gain:

Aye I mean it's not, it's not a terribly pleasant thing to do but again I feel that if the NHS are going to the bother and expense of doing these programmes then you really you've got to take part haven't you, or I feel you do anyway (screener, male, 51 years, id 14).

What emerges therefore are a group of individuals who, for a series of inter-related factors see themselves as candidates for screening, rather than candidates for colorectal cancer. Participation in screening signified prevention, healthy behaviour and reinforced the status of seeing oneself as 'a good patient' (Cromme, Whitaker, Whinstaley et al., 2016.)

Conversely, while non-screeners were not immune to feeling at risk or vulnerable to cancer, this did little to influence their screening decision. As such, relationships between perceived risk and screening decisions were not linear. Non-screeners, in common with their screening counterparts, often felt that they were no more at risk than anyone else. Although a number were more emphatic about their risk or potential risk either because of a family history or the presence of symptoms. For example, one participant who experienced severe symptoms related to bowel cancer and suspected that he did have bowel cancer was candid about his decision not to screen, stating that it was not in his 'makeup':

I thought well if I done they tests and sent them back and it became positive that I had bowel cancer then to be honest I wouldn't have wanted to know you know because it's just something in my makeup that you know what's for you is not going to go by you so if you're

going to get something like that you'll get it and I wouldn't have been prepared to go through whatever tests or operations (non-screener, male, 64 years, id 18).

Non-screeners were by no means homogenous and could be categorised into a range of key groups. Some faced practical barriers that made completing the test difficult such as issues relating to mobility, the stool itself, eyesight or literacy. As previously noted, some non-screeners had pre-existing bowel conditions that had been investigated and negated the need for screening. However, the presence of symptoms was not confined to non-screeners and though most participants had previously experienced bowel symptoms, the mere presence of symptoms was not enough to motivate or deter participation. A handful however were clear that they would 'rather not know' and their preference was to respond to symptoms rather than pre-empting illness when asymptomatic. They simply did not see themselves as candidates for screening. As mentioned above, previous studies have emphasised the nature of the test itself and the reluctance to handle faeces (Palmer et., 2014), but in this study there was little evidence that this single factor impeded participation in the screening programme. Indeed, even when the 'yuck' factor was raised by non-screeners, this was often accompanied with other views that indicate more general reluctance to screen:

Because they expect you to put your hand in the toilet and take poo out and I can't do it, that's why I didn't do it. I've tried various times, I just end up gagging and wretching so I can't do it and the other problem with it as far as I'm concerned is it doesn't actually tell you whether you've got cancer or not… they just tell you if there's blood in the stool which could be due to piles, anything, constipation causing piles which will then make you go for a test and cause unnecessary worry which will probably be negative but you've still got that worry (non-screener, female, 63 years, id 48).

The unpleasantness of the test was also discussed by screeners, but participants reflected on its inherent value. The following extract being a typical response:

I think I would rather be embarrassed for half an hour and live an extra 20 years. Why not? It's worth it. You've got to do it (screener, female, 61 years, id 22).

This extract illustrates the participant's belief of being a candidate for screening. Throughout the findings we have demonstrated that participants in this study drew on common cancer narratives when discussing their decisions around bowel cancer screening. While many participants were reluctant to identify candidates for bowel cancer or indeed consider their personal candidacy we did find, importantly, that participants instead discussed their candidacy for screening, which we will return to in the discussion.

Discussion

Our paper explored the interplay between lay epidemiology, perceived cancer candidacy and participation in bowel cancer screening. We showed that the evidence gathering mechanisms described by Davison and colleagues (1991), namely the observation of cancer events across personal and wider networks provided the basis for perceived bowel cancer candidacy, which subsequently impacts on decisions about screening. An unexpected cancer observed in someone close but crucially with more positive outcomes often prompted and provided motivation for screening. Equally observed cancer events in someone close but with poor outcomes acted as a deterrent. We found little evidence of definitive bowel cancer candidates, perhaps because few interviewees were immediately clear about risk factors associated with bowel cancer. Typically, participants offered what they regarded as 'logical' risks, such as diet, exercise and alcohol consumption though most settled on a more generic 'unhealthy' person. Therefore, the idea of candidacy for bowel cancer is not as culturally embedded as

Davison and colleagues (1991) found coronary candidacy to be. Nevertheless, we did find that participants in this study shared common cancer narratives which were brought to bear when discussing risk and these, we suggest, challenge the emergence of a risk profile that aligns with mainstream risk factors.

As previous work in cancer candidacy has demonstrated, anomalous cancer events amongst those regarded as 'fit and healthy' are foregrounded in discussions about cancer and cancer risk. That cancer is merely a lottery that can happen to anyone is a common public narrative and reinforced by the observation of unpredictable cases, which, as Davison and colleagues remind us, are most memorable (Macdonald et al., 2013). Both Austin and colleagues (2009) and Pfeffer (2004) found that those from minority ethnic communities had a clear 'cancer candidacy' in respect of both bowel and breast cancer. Both studies found that participants used cultural practice such as food or sexual behaviour to demonstrate and emphasise differences between themselves and those whom they perceived as candidates. This echoes Davison's finding whereby individuals often distanced themselves from the characteristics or behaviours of candidates. We also show a similar tendency to 'othering' (Lupton, 2013) amongst participants who were reluctant to see themselves as candidates. Yet, by emphasising the random and unpredictable nature of cancer where participants typically regard themselves as 'no more or less' at risk than anyone else, participants in this study underscored the uncertainty that envelops cancer. Rather than challenging the notion of othering we suggest that the perceived generality of cancer, like othering, provided a refuge from risk.

Despite the prevailing view that cancer can happen to anyone, participants were mindful that it does not happen to *everyone*. Bowel cancer risk is regarded as broad but non-specific. Candidacy can be a 'wide' concept, able to accommodate those at opposite ends of a

behavioural continuum (Davison et al., 1991). We argue that the risk continuum for cancer is wider still - in large part fuelled by the perceived unpredictability of the illness. Screeners' accounts hint at a general ambivalence about risk which ultimately removes 'risk' or at least the importance of 'risk factors' from their screening decisions. Removing 'risk' from screening decisions therefore challenges perceived susceptibility as a catalyst for screening participation. Non-screeners were more certain in their risk status but importantly not all saw themselves as risk free.

We found that motivations – to screen or not to screen – often reflected observations in personal, community and socio-cultural spheres. While all participants had experienced cancer within their personal or wider networks, many had limited direct experience of bowel cancer and in such cases more generic cancer evidence provided a default and suggests a nosology that is at odds with mainstream classifications (Pfeffer, 2004). Those with more experience of bowel cancer were more likely to screen and attributed their screening decision directly to the occurrence of bowel cancer in family and friends. However, there were also a substantial number of screeners who opted to screen simply because it represented a healthy choice and was viewed as part of a wider portfolio of being healthy. Indeed, implicit in many participants' accounts of screening decisions was the belief that making the decision to screen offered reassurance that they were cancer free; the test simply provided further confirmation of their 'healthy' status. To capture this we introduce the idea of candidates for screening, which we believe, is novel in the screening participation literature. Implicit in the accounts of some screeners in our study was the conviction that screening was simply something that they did, they did not feel at risk and used screening to confirm this. We propose that the invitation to screen alerts many participants to their potential risk status for the first time, thus placing them in the liminal space that is neither healthy nor ill; a consequence of the creep of

surveillance medicine (Armstrong, 1993). For participants who screen but do not believe themselves at risk, engaging in screening provides the opportunity to decrease the time spent in this in-between liminal space (Lupton, 1999). The uncertainty that flows from the projection of increased risk can be managed by the 'rational' and 'moral' decision to engage in screening (Bunton, Nettleton & Burrows, 1995).

Importantly those who saw themselves as candidates for screening had a more positive experience of cancer within their wider communities. Screening as a healthy choice adds weight to the work of others that have shown that some feel obliged to screen (Ward, Coffey & Meyer, 2015). Some participants commented on the investment of the NHS in screening programmes and their obligation to 'look after themselves'. Again, this is tied to the recent work on the importance of the 'good patient' and the need for patients to be custodians of the NHS (Cromme et al., 2016). Those who saw themselves as candidates for screening also emphasised their identity as good patients, obliged to invest in prevention.

Non-screeners were more convinced of their risk status – whether at risk or not. Yet just as screening was a rational response for some, not engaging in screening was equally rational for those who decided not to screen. Though heterogeneous, non-screeners were less likely to have personal experience of someone with bowel cancer and simultaneously more likely to have a negative view of cancer. Often the cases they discussed emphasised harrowing treatment, pain and death and did not discuss the benefits of early detection, despite being favourable towards the ethos of screening. Non-screeners certainly articulated the 'rather not know' position, a position that has been commonly reported in other studies (Bradley et al., 2015; Honein-AbouHaidar et al., 2016; Lipworth, Davey, Carter, Hooker & Hu, 2010) though some went further by stating that they would know if they had cancer because they

were sure that they would experience symptoms, which echoes work done by others (Austin et al., 2009).

As previous studies of candidacy have demonstrated (Davison et al., 1991; Macdonald et al., 2013; Pfeffer, 2004) candidates provide a comparative benchmark and participants frequently stressed how they differed from – or indeed were similar to – people that they knew with cancer and this comparison often contextualised screening decisions. Knowing someone 'like you' previously regarded as not 'at risk' but with a cancer prompted screening and screening assisted in managing any uncertainty, just as deciding someone was not like you justified decisions not to screen. Bradley and colleagues (2015) report that non-screeners commented on the extent to which their position was characterised by inherent tensions. In our study, most non-screeners value screening, would urge others to screen but they rationally decide that they are not candidates for screening.

We found little evidence from the data to support a linear relationship between feelings of risk and screening decisions. Instead what we found was a complex interplay between individual perceptions of risk and susceptibility and community observations that provide the contingent context in which screening decisions are made. Both screeners and non-screeners reported that they felt at risk but importantly for screeners this was general rather than specific. Some non-screeners preferred not to know and, in the absence of symptoms, did not see themselves as candidates for cancer. Other studies have found similar results (Macdonald et al., 2013; Pfeffer, 2004).

Finally, our findings offer an empirical contribution to theoretical understanding of risk (Zinn 2008; Zinn 2016). Zinn challenges the rational/non-rational polarity and proposes that several

'in-between strategies', such as emotion, trust and hope are employed in decision making processes. As we outlined in our introduction, national screening programmes measure success via participation rates and therefore seek to encourage uptake. It follows therefore that the expert orthodoxy equates screening participation with rational choice, albeit implicitly. Our findings demonstrate that those who decided to participate in screening were often more ambivalent about risk, equally likely to see themselves simultaneously at risk and not at risk. They described the influence of observations in personal and social lifeworlds (Brown 2016) as well as culturally embedded notions of the 'good patient' are evoked in decision making processes and the decision to screen was rarely a straightforward objective assessment based on bowel cancer risk algorithms. Rather they regarded themselves as candidates for screening which was viewed as a natural extension of a 'healthy lifestyle' and provided reassurance that they did *not* have cancer. Therefore, trust and intuition were being enacted in decisions to screen. Zinn (2008) suggests that trust, intuition and emotion often lie beneath decisions to take risks. Our findings show that these in between strategies are also drawn on to arrive at what would be regarded as the 'rational' outcome; to participate in screening. Conversely those who decided not to screen were more certain about their risk status and saw themselves as either at risk or not at risk. Their decisions were based on more reasonable or rational strategies; the presence or lack of symptoms. However, they arrived instead at what could arguably be perceived as a non-rational position.

Conclusions

Although screening decisions were made by considering a wide range of factors, often participants saw screening as part of a wider portfolio of being healthy and felt obliged to look after themselves. Rather than candidates for bowel cancer, screeners therefore viewed themselves as candidates for screening. For many, screening decisions pointed to the

acceptance and normalisation of the rhetoric of personal responsibility for health. Screening decisions are moral decisions. The parameters of risk were at once widened, yet simplified, to a binary 'healthy' or 'unhealthy' encapsulated in a series of key preventive behaviours, including screening. Yet, as we have demonstrated, anomalies challenge perceptions of cancer candidacy and result in individuals questioning the credence of health education messages. Thus, uncertainty is heightened and ambiguity featured strongly in screeners' personal perception of risk. Many screeners felt that they were no more or less at risk than anyone else, which mirrors the perception of risk as wide. Such a wide categorisation of 'risk' is in danger of becoming meaningless. It is notable that non-screeners were often more certain, believing either that they would know if they were ill or that they would definitely prefer not to know if they had cancer. These two opposing positions are essentially at odds with screening programmes that promote the offer of certainty. Our findings have related theoretical and practical implications; the moral structure that underpins the new public health can be witnessed practically in the way in which those who see themselves as candidates for screening embrace wider positive health practices.

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No potential conflict of interest was reported by the authors.

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Table 1. Socio-demographics by screeners and non-screeners

	Screeners	Non-screeners	Total
Age group			
50-54 years	7	3	10
55-59 years	5	3	8
60-64 years	3	4	7
65-70 years	13	9	22
71+	9	5	14
Gender			
Male	17	13	30
Female	20	11	31
Level of deprivation			
SIMD 1+2 (most deprived)	20	13	33
SIMD 3	5	4	9
SIMD 4+5 (least deprived)	12	7	19